Involving People in Research

Learning Resources

About this document

This document was created in 2024 as a learning resource to support researchers from multiple disciplines to plan, do, report and evaluate involvement in research.

This document and the resources in it were created and adapted by Jack Nunn for La Trobe University, 2024. This document was produced for the webinar 'Introduction to Public Involvement'.

Some content is adapted from "Building Research Partnerships", with the content used created by Jack Nunn for Macmillan Cancer Support[1], "Involving the Public and Consumers in Cancer Research", created by Jack Nunn for the Victorian Comprehensive Cancer Centre (VCCC)[2], 2016, and 'A Guide to Planning Involvement In Research', produced by Jack Nunn for the charity Science for All[3].

Some resources are adapted from Australian Federal Government information, used and adapted under Creative Commons Attribution 3.0 licence (where this is the case, each resource states the source URL).

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This manual is Version 4 and any feedback is very welcome. Please note all content is shared for education and development purposes.

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A 'living' version of the STARDIT report relating to this document can be found here.

Contents

Resources

These learning resources have been shared to aid learning, and to be used as part of facilitated learning events. They are shared under Creative Commons so that anyone can adapt and use them for free (under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License).

Resource 1: Involving the public - what, who and how?

Getting our words right

It is important that the language used to describe involvement is inclusive and does not unintentionally exclude anyone. Sometimes people may get involved on behalf of themselves, communities defined by shared interests or diseases. Beyond health and medical research, people might get involved in research on behalf of specific species and ecosystems, or whole environments.

As words such as 'engagement', 'involvement' and 'participation' are often used interchangeably, careful articulation is required. Similarly, to be meaningful, words such as 'stakeholder', 'patient', 'public', 'community', 'consumer' and 'payer' also need shared definitions. While terms such as 'people' or 'the public' may exclude fewer people, they also lack specificity. Ensuring words and actions reflect the values of multiple stakeholders can show people that their needs, priorities and interests are inherently valuable and integrated into the research process. In extreme cases, using the wrong words can perpetuate structural violence, discrimination and systemic racism.

Accordingly, it is important to involve stakeholders in helping co-define language, and check that terms being used are acceptable, appropriate and understandable. A short glossary of terms and what is meant by them can be found in the section 'Terminology and definitions'.

Who is involving whom?

Involving the public in research requires an attempt to balance individual autonomy and collective values, in order to ensure the benefits of research and human knowledge are shared equitably. Variation in people's priorities means that it is important to try to articulate the differences and decision-making processes in a transparent way. Public involvement must be inclusive, and institutions such as La Trobe have a moral and legal responsibility to ensure everyone has been supported to get involved in research.

When we say involving the public in research, we include people from any communities of shared interest, people who use health or care services, (including patients, carers, service users), consumers or users of specific technology or services, people with specific personal experiences, people from specific cultural or linguistic communities, people from communities defined by recent shared ancestry, people affected by specific environmental phenomena, and the general public.

According to La Trobe University Act 2009, 'public' includes both Australian and international communities.

The interrelationship between the terms 'engagement', 'participation' and 'involvement' in the context of research is illustrated in the 'Diagram of engagement, participation and involvement in research', and a full articulation of the word 'stakeholder' is provided in the section 'Stakeholder Groupings'.

Stakeholder Groupings

The table below articulates the different stakeholder groupings implied by the word 'stakeholders', in the context of research, policy and services. It is important to note the word 'groupings' is used, to recognise that the act of grouping people can either be done collaboratively (with people) or done to people, without their involvement or consent.

Unintended harms can be caused by grouping people and creating descriptions about communities that are not in alignment with the way the people from those communities view themselves. Grouping people in ways which do not align with their own values or beliefs can perpetuate structural violence towards people, especially when research is done 'on' people, rather than with them. For example, some people who identify as members of the 'Deaf community' believe that being deaf is a form of human diversity, and need not be understood as a disease or disability.
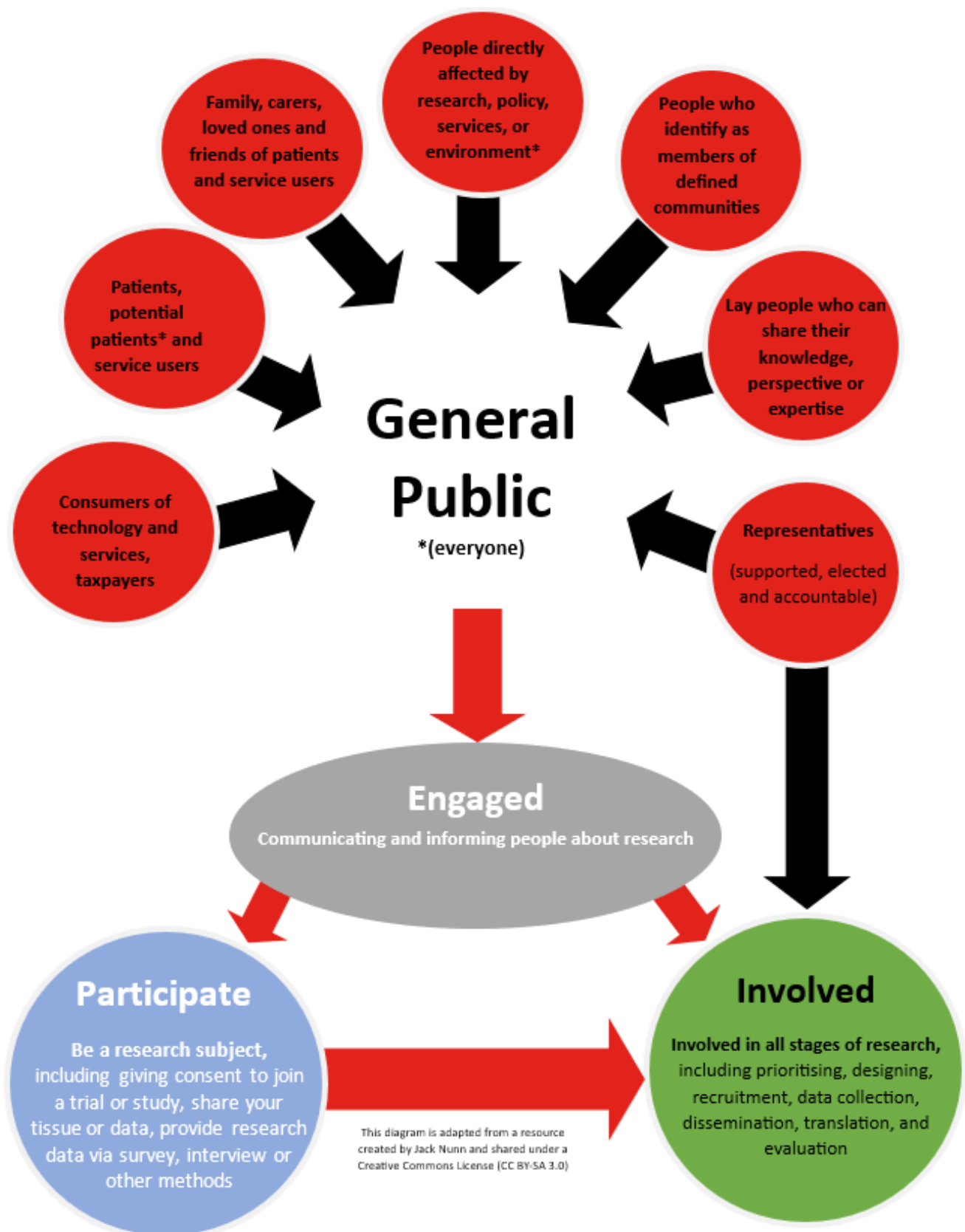
When working with Indigenous peoples in countries such as Australia, it is of particular importance to understand and acknowledge both the history and continued evidence of systemic racism and structural violence towards Aboriginal peoples. The La Trobe University Act (2009) articulates the legal responsibility to 'use its expertise and resources to involve Aboriginal and Torres Strait Islander people of Australia in its teaching and learning, research and advancement of knowledge activities' and contribute 'realising Aboriginal and Torres Strait Islander aspirations' and 'safe guarding of the ancient and rich Aboriginal and Torres Strait Islander cultural heritage'.

Ensuring words and actions reflect the values of multiple stakeholders can show people that their needs, priorities and interests are inherently valuable and integrated into the research process in a way which extends beyond simply improving recruitment for a study. The table below summarises some of the more common stakeholder groupings, and articulates further what can be meant by the term 'the general public'.

	Stakeholders				
	Industry		**Research and educational Institutes**	**Government**	*Public*
	For-profit	Not-for-profit (charity)	University Independent	Departments and Committees (local, State and Federal)	(See diagram on next page)
	Investors, share-holders	Donors	Researchers and educators	Elected representatives, civil servants, and Government employees	
	Employees, casual workers, consultants, and paid advisors				
	Owners of intellectual property, physical property, and goods				

(Left margin labels: Organisations, People)

Please note: in the table above, 'government' has been included as a stakeholder, although technically in a representative democratic system (such as Australia) , the general public is the stakeholder which has devolved governance and decision-making to elected representatives and 'public servants' who, in theory, act in the public interest.

Diagram of engagement, participation, and involvement in research

Family, carers, loved ones and friends of patients and service users

People directly affected by research, policy, services, or environment*

People who identify as members of defined communities

Patients, potential patients* and service users

Lay people who can share their knowledge, perspective or expertise

Consumers of technology and services, taxpayers

General Public
*(everyone)

Representatives (supported, elected and accountable)

Engaged
Communicating and informing people about research

Participate
Be a research subject, including giving consent to join a trial or study, share your tissue or data, provide research data via survey, interview or other methods

This diagram is adapted from a resource created by Jack Nunn and shared under a Creative Commons License (CC BY-SA 3.0)

Involved
Involved in all stages of research, including prioritising, designing, recruitment, data collection, dissemination, translation, and evaluation

Terminology and definitions

Words can mean different things to different people. The important thing when using a word or phrase, is to define what **you** mean by it, and be consistent. Some common words and the related concepts are defined in this resource. Some words and concepts are linked to WikiData in order to standardise terminology where possible. Created in October 2012, "Wikidata is a large-scale, human-readable, machine-readable, multilingual, multidisciplinary, centralized, editable, structured, and linked knowledge-base". Terminology in these definitions has been informed by multiple sources, including the International Association for Public Participation (IAP2) 'Public Participation Spectrum'.

Table 1: Defining words and concepts

WORD (WIKIDATA ENTRY)	DEFINITION
Barriers (Q109580927)	Barriers refers to things that might prevent something from happening.
Community (Q177634)	A group of people sharing a common interest or values (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different types of communities are likely to have different perspectives and approaches to their involvement in research. (NHMRC definition)
Consumer	Consumer –The NHMRC states consumers are 'patients and potential patients, carers, and people who use health care services' (in the Statement On Consumer And Community Involvement In Health And Medical Research)
Enablers (Q109580938)	Enablers refers to things that help enable something to happen. For example, paying people's travel expenses might enable them to get involved in research.
Engagement (Q120727104)	When information and knowledge about research is shared with the public so that they are better informed on why, how, where and by whom research is conducted. When people are engaged they are being 'told' about something, rather than 'doing it'. **Note**: As 'engagement' and 'involvement' are used interchangeably by some, the definition of engagement above in this Strategy is used to distinguish it from the active involvement of stakeholders. (Adapted from Australian Genomics Guidelines for Community Involvement in Genomic Research)
Lay person (Q120943280)	The word 'lay' comes from the Greek word 'laikos' which means "of the people". A layperson has come to mean someone who is a non-professional in a given area of knowledge. In the context of research, it describes someone who is not qualified in a certain area, but recognises the value of the 'non-expert' perspective they have. The term 'lay person' therefore refer to any member of the public who is a non-expert in a specific area of knowledge (hence a 'lay' summary being a summary written for anyone to understand). Examples in context: "Lay involvement in the analysis of qualitative data in health services research" https://doi.org/10.1186/s40900-016-0041-z

WORD (WIKIDATA ENTRY)	DEFINITION
Open Science (Q309823)	The UNESCO Recommendation on Open Science defines open science as "an inclusive construct that combines various movements and practices aiming to make multilingual scientific knowledge openly available, accessible and reusable for everyone, to increase scientific collaborations and sharing of information for the benefits of science and society, and to open the processes of scientific knowledge creation, evaluation and communication to societal actors beyond the traditional scientific community. It comprises all scientific disciplines and aspects of scholarly practices, including basic and applied sciences, natural and social sciences and the humanities, and it builds on the following key pillars: open scientific knowledge, open science infrastructures, science communication, open engagement of societal actors and open dialogue with other knowledge systems" • Example in context: "as a global public good, open science should belong to humanity in common and benefit humanity as a whole"
Participation in research (Q120727340)	Participation in research is where a person voluntarily partakes in human research after giving informed consent to be the subject of the research as a passive participant. **Note**: As 'participation' and 'involvement' are used interchangeably by some, 'participation' has been defined in this Strategy as above to avoid confusion between 'involving the public in research', and the ethically distinct act of participation in research. (Adapted from Australian Genomics Guidelines for Community Involvement in Genomic Research)
Participatory action research (Q7140444)	Participatory action research is an umbrella term which describes a number of related approaches, including forms of action research which embrace a participatory philosophy and include 'co-design' and 'co-production' of research.[1] It is a process whereby researchers, the public and other relevant stakeholders "work together, sharing power and responsibility from the start to the end of the project", including knowledge generation and translation.[2]
Public interest (Q29627)	A sense of "common well-being" or "general welfare" of the public, society or humanity. The term is used specifically in the context of human society, rather than environmental systems.
Public involvement (Q124607879)	When anyone from the public can be actively, transparently and meaningfully involved in a process, including influencing the development, implementation, and evaluation of policies, initiatives, research and services that impact them.
Public involvement in research (Q109581008)	Public involvement in research refers to research being carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. This can include working to prioritise research topics, helping design research, helping manage it, and helping evaluate it. (Adapted from INVOLVE 'What is public involvement in research?')
Representative (Q11997597)	A person who speaks for or acts on behalf of another person, or a defined group or community. This includes taking part in the decision-making process on behalf of others.

WORD (WIKIDATA ENTRY)	DEFINITION
Stakeholder (Q109581040)	The term 'stakeholder' is used here to mean anyone who has a 'stake' in research, services, policy, products or other initiatives. In particular, the term includes those with important knowledge, experiences, expertise or views that should be taken into account. It can include: researchers, research funders, policy makers, people affected by the research, people with specific health conditions, people with specific genomics variations, patients, and the general public (including 'tax-payers' for publicly funded research).
The public, 'general public' or 'people' (Q2388316)	The term 'people' and 'the public' is used to refer specifically to patients, potential patients, carers, payers, consumers of health technology and the general public, excluding professional researchers, research funders, policy makers and anyone else with a professional connection to research. The public is everyone in society, and the term may extend beyond national borders to encompass all humanity. The NHMRC states "Collectively, 'consumers' and 'community members' may be referred to as 'the public'" (in the Statement On Consumer And Community Involvement In Health And Medical Research)

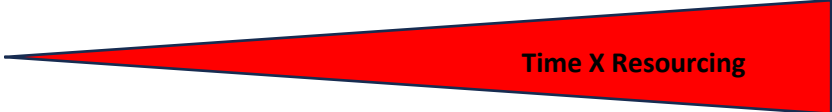## Resource 2: A Guide To Planning Involvement In Research

Planning how different stakeholders will be involved in research should be an intrinsic part of the research plan, with a distinct method and appropriate resourcing (budget and staff time).

Ideally, this 'Involvement Plan' should itself be co-designed with appropriate stakeholders to ensure the plan is appropriate, realistic and not exploitative. Planning for involvement should start as early as possible, with involvement activities ideally shaping the research project or question, sometime well before a project is itself funded.

The following guide divides planning for involvement into three distinct stages, which will ideally take place before the research begins. This guide has been written as a series of reflective questions to help you consider different aspects of the Involvement Plan.

Stage 1: Reflection, mapping and planning

- **What are you doing and why?**
    - Do you or your colleagues have a clear idea of who is doing what, or you plan to do?
    - Why are you doing it? What are **your** motivations? Are everyone else's motivations clear to everyone else? Do you, your colleagues or organisation have stated values?
    - Are you supported sufficiently? Do you have enough time to do this?
- **Why do you want other people involved?**
    - What is the motivation? Is it to improve the quality of research, the relevance or the dissemination and translation of the research? Is it to ultimately improve lives?
- **Who will be involved and how?**
    - **Who is doing which tasks?** Are there different stakeholder groupings?
        - Groupings can include: Professional researchers, experts, people directly affected by the research, people with specific experiences which can inform the research, interested members of the general public
        - What might enable or inhibit their involvement? What support might they need to be involved?
            - Who is being paid, who isn't?
            - Have you budgeted for staff or researcher time, including for the Involvement Plan
            - Will you offer training?
            - Will you offer other appropriate support? (paying for travel, IT equipment, emotional support)
    - **What methods will you use?** Co-*what*?

Consultation?	**Co**-creation?	**Co**-investigator?
Time X Resourcing		
Conduct surveys	**Co**mmittee	**Co**lleague or Co-author

- **What communication modes will you use?**
    - In person meetings? Video calls? Emails and shared documents? Online text-based discussions? Telephone interviews? Online surveys?
- **How, where and when will you recruit stakeholders to be involved?**
- **Do you need ethics approval for your involvement plan?**

Once you have a draft 'Involvement Plan', recruit a number of stakeholders to review and refine it. For example:

Method	Interim Steering Committee
Tasks	1: Review and comment on involvement plan 2: Collaboratively map stakeholders 3: Collect information about different stakeholders' preference for involvement (some stakeholders might prefer different methods or communication modes) 4: Report different 'interests' of stakeholders (personal, professional or financial interests) and if there are any 'conflicting' or 'competing' interests
Modes	Video calls, commenting on shared documents
Recruitment	Public link to expression of interest or application *or* invite only
Enablers	People will be paid $100 an hour and offered training and appropriate support
Resourcing	Appropriate resourcing (including budget and staff time) has been allocated
Ethics	Ethics approval has been granted for this Involvement Plan

Stage 3: Begin the Involvement Plan

On the next page, 'Figure 1: Public Involvement in Research' summarises the research cycle, and gives examples of tasks that the public (including patients, carers, communities and consumers) can be involved in.

If your project is still at the conceptual or design stage, 'Figure 2: Public involvement and Research Design' provides a simplified 'design cycle' (which is itself part of the research cycle), and gives examples of tasks that the public can be involved in.

While it is best practice to plan how you will involve the public in each stage of the research from the start, you can still start planning at any stage of the research, even if it's just for the final stages.

How do we involve the public in research?

We can involve the public in research by actively supporting people to be involved in:

- **shaping our priorities and what we do** - ensuring our research is relevant and acceptable
- **defining what is likely to be acceptable to the public** – particularly in ethically sensitive research
- **improving the research process** – making it easier for the public and prospective participants to understand the research and its potential risks and benefits
- **improving the experience of participants in research** – including checking the methods are appropriate and ethically acceptable for human or non-human research participants
- **improving the interpretation of data and evaluation of the research** – including interpreting data and evaluating research methods
- **improving the communication** – including sharing data, findings and involving people in implementing learning from research
- **improving the impact assessment of the research** – including unexpected or unintended impacts

This section was p*artially adapted from https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement*
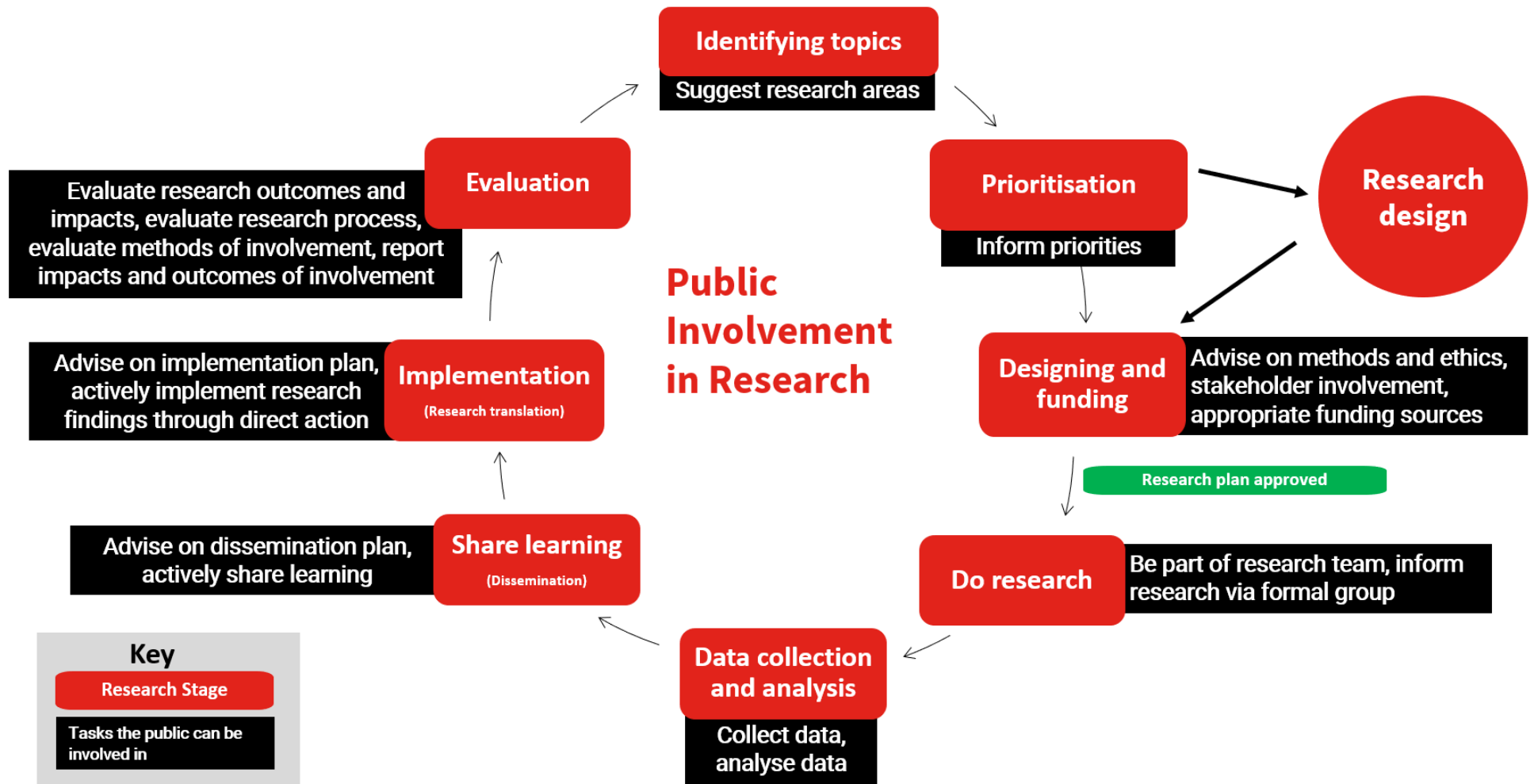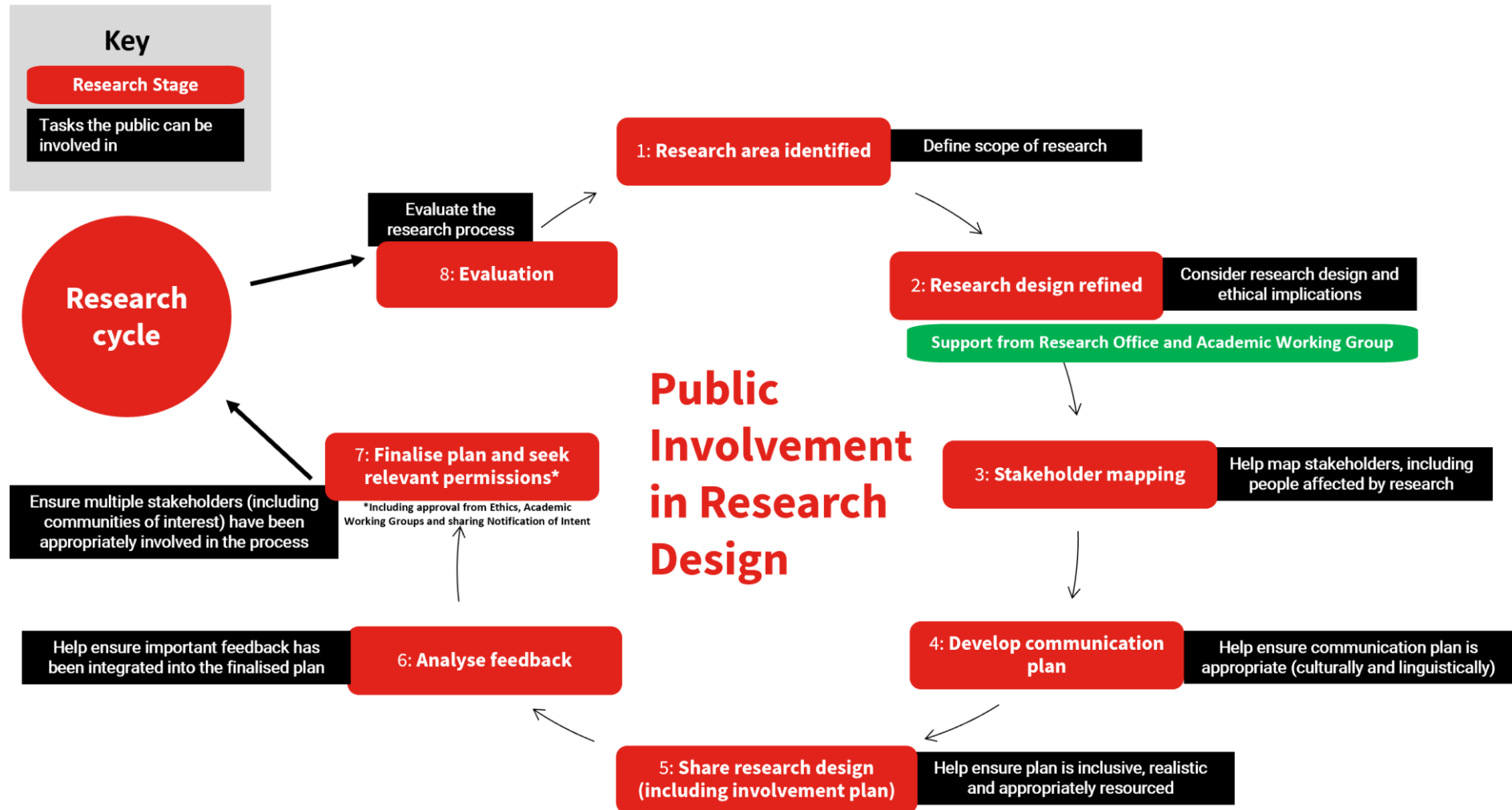
Figure 1: Public Involvement in Research

Public Involvement in Research

- **Identifying topics** — Suggest research areas
- **Prioritisation** — Inform priorities
- **Research design**
- **Designing and funding** — Advise on methods and ethics, stakeholder involvement, appropriate funding sources
- Research plan approved
- **Do research** — Be part of research team, inform research via formal group
- **Data collection and analysis** — Collect data, analyse data
- **Share learning** (Dissemination) — Advise on dissemination plan, actively share learning
- **Implementation** (Research translation) — Advise on implementation plan, actively implement research findings through direct action
- **Evaluation** — Evaluate research outcomes and impacts, evaluate research process, evaluate methods of involvement, report impacts and outcomes of involvement

Key
- Research Stage
- Tasks the public can be involved in

Figure 2: Public involvement and Research Design

Reporting involvement

At which stages of the research do you intend to report your research plan and involvement plan?

For example, you could publish your research plan and involvement plan by publishing a peer-reviewed protocol. You can also report it retrospectively in a peer-reviewed publication.

A novel way of planning and reporting is using 'Standardised Data on Initiatives (STARDIT)' to report at each stage, with the report marked as prospective, ongoing or completed. You can update it at each stage, make changes and involve multiple stakeholders in creating, editing or verifying it. Learn more here:

ScienceForAll.World/STARDIT

The 'Resource 3: A Template for Planning and Reporting Involvement In Research' been written to align with the 'Standardised Data on Initiatives' (STARDIT) reporting tool.

STARDIT has been recommend for us by Australian Genomics. For more information, visit: ScienceForAll.World/STARDIT

Other tools to report involvement include including:
- Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) reporting checklists
- Public Involvement Impact Assessment Framework (PiiAF)

By reporting your planned involvement **before you start**:
- You can demonstrate to stakeholders how you plan to involve people, and let them assess if they think this is realistic, appropriate and acceptable
- Allow potential funders to assess the level of stakeholder involvement, and if this is appropriate

By reporting your involvement once it is ongoing and completed:
- You can help people critically appraising your research in deciding how stakeholder involvement influenced the research
- Help others learn from your involvement, especially by sharing barriers, enablers, impacts and outcomes

Resource 3: A Template for Planning and Reporting Involvement In Research

By completing this template, you will have outlined the plan for the research, including how different people will be involved in different tasks. All categories are aligned with STARDIT data fields, which can be used to report the initiative at all stages. Please note as this is a planning template the future tense is used, but present and past events can also be reported. Please note the data fields here are the 'Minimum Contribution' fields, further are available when completing the report. Visit: ScienceForAll.World/STARDIT

Section	Data fields	Guidance for completing the data field		
Initiative context	Initiative name	What is the name or title of the project, initiative or research?		
	Initiative type	Is it research, arts, education, policy, information, media, product, health and social care services?		
	Description	Summarise the project in 1500 characters in plain language as if writing for a 'non-expert' audience		
	Aims	What are the goals, objectives or purpose of this initiative?		
	State	Is this report about an initiative which is **prospective**, **ongoing** , or **completed**?		
	Location	What is the geographical scope of this initiative? For example, 'Australia' or 'global'		
Report Authors	Report authors	Who wrote this report? Who checked the report? Who contributed in other ways (such as editing information)		
	Contact	Is a report author a contact for the initiative? Is the report author affiliated or unaffiliated with the initiative?		
Contributor information	Contributors	**Type**: Who will contribute to this initiative? This can be an '**individual'**, '**grouping of individuals'** or an '**organisation'**. Example: 'Grouping of individuals'	**Name**: What is the name of the individual, grouping of individuals (number?) or organisation? Example: Project Steering Committee (10)	**Tasks** (current status): What are the tasks of **individual**, **grouping of individuals** or **organisation** (or planned or completed)? Example: project design (completed), management (ongoing) and data analysis (planned)
	Method	How will this contributor involved? Example: formal committee with Terms of Reference		
	Communication	What modes of communication will be used? Example: In person meetings, video calls, shared online documents?		
	Recruitment	How will people be recruited or invited to contribute to the initiative? Example: Public web-link, email invite		

Section	Data fields	Guidance for completing the data field
	Compensation	How will this contributor be compensated or remunerated? Example: payment, honorarium, gift, no compensation
	Cost	What was the estimated financial cost for involving each individual, grouping or organisation who contributed?
Other inputs	Financial	What are the estimated financial inputs for this project (how much will it cost?), describe who is paying and provide and public links to information
	Time and 'other'	How much time is being given to this project? For example, 'in-kind', pro bono or voluntary hours? Any other resources?
Ethics	Ethics status	Does this initiative need ethics approval? Example: 'Not applicable', 'ethics approval being sought' or 'approved'
	Ethics details	Which organisation provided approval? What was the date? What is the ID? Can you provide a link to it?
Assessing Inclusivity	Enablers of contribution or involvement	What are the anticipated factors which might enable people to contribute or be involved in the initiative? Example: paying people for time or travel, using accessible technology to conduct online meetings
	Barriers of contribution or involvement	What are the anticipated factors which might inhibit or prevent people from contributing or be involved in the initiative? Example: Not paying people for time, not offering any translation services, only meeting in-person (not online)
Contribution Information	Contributor Interests	What are the financial, personal, professional or other interests of the contributor (including conflicting or competing interests)? Example: All members of the Project Steering Committee are people living with or caring for people with dementia
	Contributor Impacts	What **changes to the initiative** do you anticipate or report as a result of this contribution? Example: The Project Steering Committee changed the scope of the research project from just researching the experiences of people with dementia, to including parents and carers of people with dementia
	Impact stage	What date or stage of the initiative did this impact occur? Example: Planning stage, implementation, data analysis

Section	Data fields	Guidance for completing the data field
Outputs and impacts	Output type	What is the type of output? Example: Publication, report or document ? Dataset? Event? Change? Learning item? Knowledge translation? Other type?
	Output description	What came from the work done (e.g. changes made, events held, data and documents produced, things learnt or other results)? When describing these, attempt to label which groupings were affected and how. These can include impacts on people, organisations, processes or other kinds of impacts.
	Learning	What new knowledge was generated? If appropriate include effect size, relevant statistics and level of evidence
	Knowledge translation	How what was learnt **has** or **will** be used
	Impact of output	Impact or effect of the output

This resource is adapted from 'A Guide to Planning Involvement In Research', produced by Jack Nunn for the charity Science for All,
https://archive.org/details/a-guide-to-planning-involvement-in-research-v-1-2024.01.15

Resource 4: Activity instructions

These activities can be done as an individual or as a group. They are designed to encourage reflection and planning in relation to involving different stakeholders in research.

Activity 1: Stakeholder Mapping

Instructions: list all the different stakeholder groupings relevant to the research project - groupings include:

- Researchers, investigators, partners, stakeholders (including 'patients', 'consumers' and the 'public'), research participants, industry, government, academia, community (defined by geography or shared interest?)
-

Note that people should pay particular attention to thinking about who the research is intended to benefit

Activity 2: Which stakeholders are doing which tasks?

If you are still designing your research – consider which stakeholders would you involve in the following tasks?
o   Identifying ideas (research questions, methods, interventions)
o   Refining idea, research question, method and intervention (e.g. who could give feedback?)
o   **Stakeholder mapping** (**you've** done **your** initial mapping, but which stakeholders might be good to involve in further mapping – e.g. community members might know of relevant local organisations)
o   **Develop a communication plan** (who will you tell about this initiative, what modes of communication, who will help you tailor it to various audiences/stakeholder groupings?)
o   Share information about this idea or initiative, including the Involvement Plan (who will be involved, which tasks, what methods, what communications modes?)
o   Analyse feedback on the idea or initiative (including feedback on the involvement plan)
o   Finalise the plan and seek relevant permissions (ethics, consent, land owners, traditional custodians)

Activity 3: Mapping interests, preferences and support needs

What are the different 'interests' of your stakeholders? Do different stakeholders have different preferences for different ways of working? (online, in person, synchronous/asynchronous)

o   Mapping interests
   - Which of these stakeholders or stakeholder groupings has an 'interest' and what kind of interest? (personal, professional, financial, other?) – could it be perceived as a conflicting or competing interest?
o   Mapping preferences
   - Might different stakeholders have different preferences for ways of working (methods of being involved, communication modes?)
o   Mapping support needs
   - What different support needs might different stakeholders have?
      o   **Financial**: can everyone afford to volunteer? Who will you pay for their time or travel
      o   **Practical**: how can you use accessible technology to involve people?
      o   **Learning**: what learning needs might different stakeholders have?
      o   **Emotional**: Do you need to consider supporting people's emotional needs?

Activity 4: The research cycle

If you've worked through the design cycle, you can work through the research cycle.
For each one of these stages of the research cycle, consider the following questions:

- **Sharing idea** – who is involved in giving feedback, how? Who is paid, who isn't? Who has an 'interest', and what kind of 'interest'?
- **Prioritisation** – is this a priority? For who? Why? What else might be a priority? Who have you involved in identifying topics and prioritising them (See: James Lind Alliance Priority Setting Partnerships)
- **Designing and resourcing** – where is the most appropriate place to get funding? If you have been funded, do you need additional funding or resourcing? Have you involved stakeholders in identifying other funding sources, and exploring other kinds of in-kind support or resourcing?
- **Do initiative** – who is doing which tasks at which stages? (this is a big one!)
- **Data collection and analysis** – who is collecting it, analysing it, checking it. Who is involved in checking your data storage plan?
- **Sharing learning** – who is a co-author? (who is paid?), where are you sharing results and learning, what data are you sharing, what data aren't you sharing? Who was involved in deciding this?

Activity 5: Planning and reporting

How are you planning your research plan and the involvement plan? At which stages of the research do you intend to report your research plan and involvement plan?
For example, you could publish your research plan and involvement plan by publishing a peer-reviewed protocol (which is always a good thing to do – but sometimes by the time it's published, the project is halfway completed!)

A novel way of planning and reporting is using 'Standardised Data on Initiatives (STARDIT)' to report at each stage, with the report marked as prospective, ongoing or completed. You can update it at each stage, make changes and involve multiple stakeholders in creating, editing or verifying it. Learn more here: ScienceForAll.World/STARDIT
You can complete a plan using the shared working document (link shared in chat), or by working through Resource 3: A Template for Planning and Reporting Involvement In Research.

Resource 5: Key information from MRFF about involvement

This resource is adapted from 'Principles for Consumer Involvement in Research - Advice from the Medical Research Future Fund Consumer Reference Panel – March 2023' https://www.health.gov.au/sites/default/files/2023-03/principles-for-consumer-involvement-in-research-funded-by-the-medical-research-future-fund.pdf
Document adapted under [Creative Commons Attribution 3.0 licence](https://www.health.gov.au)

Summary of consumer involvement in MRFF

Consumers are the ultimate funders, users and beneficiaries of health and medical research and innovation. They have valuable contributions to make to research and a right to be involved. Many consumers want to be involved in health and medical research and to be involved beyond a role of 'participant' or 'subject'.

The object of the Medical Research Future Fund (MRFF) is to improve the health and wellbeing of Australians. Our collective ability to achieve this is enhanced by effectively involving consumers in the prioritisation, design, conduct, translation and evaluation of research funded by the MRFF as well as in the selection of funded research projects.

Consumers bring a broad range of valuable perspectives and experiences, such as diversity in culture, linguistics, gender and ability, that can improve the quality, relevance and impact of research.

There is evidence that involving consumers can build trust between researchers and consumers[2], increase recruitment of participants[3] and improve the quality, outcomes, relevance and impact of the research.[2,4]

Strengthening consumer involvement in MRFF-funded research is important to align Australia's health and medical research conduct with international best practice, and to further build the quality and international competitiveness of Australian research.

Strong and effective consumer involvement requires strong consumer engagement skills and approaches by research teams, adapted to each unique project. It also requires engagement from, encouragement by, and facilitation through, all areas of the health and medical research sector – including but not limited to research funders, research organisations, researchers, professional bodies, industry, consumer organisations, consumers, and community members.

[2] A Anderst et al, 'Engaging consumers in health research: a narrative review', *Australian Health Review*, 2020, 44(5): 806-813, doi.org/10.1071/AH19202.
[3] J Crocker et al, 'Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis', *BMJ*, 2018, Nov 28;363:k4738, doi: 10.1136/bmj.k4738.
[4] J Brett et al, 'Mapping the impact of patient and public involvement on health and social care research: a systematic review', *Health Expectations*, 2012, 17: 637–650, doi.org/10.1111/j.1369-7625.2012.00795.x.

Principles for Consumer Involvement in Research Funded by the Medical Research Future Fund

Advice from the Medical Research Future Fund Consumer Reference Panel

A consumer is a person with lived experience as a patient, client, potential patient, user of health services, and/or providing support as a carer, family or community member.

It is the view of the Consumer Reference Panel that to achieve the best quality, outcomes and value for money in MRFF funded research, consumers should be involved:

☐ **In every type of research**, including basic science, public health, preventive health, translation and clinical research.

☐ **At all stages of research**, from defining the need/priority of a research question, refining the research question and research design through to conduct of the research and sharing and translation of results.

☐ **In partnership with researchers,** with consumers respected and recognised for the valuable and complementary knowledge, expertise and perspectives they bring to the research.

☐ **Effectively**, with sufficient time, resources and depth of relationships to enable consumers to understand and actively engage with and contribute to the research.

☐ **Sensitively and safely,** through research teams with strong and broad capacity and capabilities in consumer involvement, appropriate training and a supportive environment for consumers, and clearly defined and agreed roles.

☐ **With broad diversity and equity**, with the goal of increasing involvement of priority populations through culturally safe and appropriate engagement.

The form and level of consumer involvement should be appropriate to the specific project and to that cohort of consumers.

The Consumer Reference Panel has also put together guidance for researchers on what these Principles could look like in practice. This guidance is provided at Attachment 1.

Attachment 1 - Implementation Guidance

The Consumer Reference Panel has provided the following advice to support researchers, research organisations, other relevant stakeholders and consumers to achieve best practice consumer involvement as a strategy for supporting the best possible outcomes from MRFF funded research.

While expected across all research projects, it is noted that addressing every dot point below in every research project is aspirational. Also, the form and level of consumer involvement should be appropriate to the specific project and to that cohort of consumers.

To achieve best practice consumer involvement, MRFF grant applicants and prospective grant applicants would:

- Build ongoing, productive, two-way relationships with consumers, consumer representatives, consumer advocates and consumer organisations, as appropriate to their area of research
- Engage with diverse communities as relevant to their area of research, including Aboriginal and/or Torres Strait Islander people, culturally and linguistically diverse people, older people experiencing diseases of ageing, people with rare or currently untreatable diseases/conditions, people in remote/rural communities, people with a disability, LGBTIQ+ people, and youth
- Work with consumers to understand consumer priorities
- Involve consumers in defining the need, priority and framing of the research question
- Regularly consult with consumers to understand how consumers want to be involved in the research project through design, conduct, dissemination and translation
- Work with consumers to co-design the research project

To achieve best practice consumer involvement, within an MRFF grant application, applicants would:

- Describe how their project aligns with consumer needs, values and priorities and benefits consumers and how this alignment has been achieved
- Describe how, when and in what roles consumers have been and will be involved in the ongoing conduct and dissemination of the research (e.g., governance, oversight, recruitment, consent, ethics, communications, publications, translation, as a chief/associate investigator)
- Describe how consumer involvement is embedded across various project governance levels, and ensures sufficient peer support for consumers (e.g., more than one consumer on each committee)
- Describe how consumer involvement is inclusive and diverse, as appropriate to the project (e.g., age, gender, geographic association, socio-economic status, cultural and linguistic diversity). If they have excluded groups from their research population, explain why

- Describe how effective support, training and information will be provided to consumers to allow consumers to contribute to their full potential
- Describe how an environment where consumer involvement is safe, sensitive and respectful will be provided

- ☐ Outline how their research team has the appropriate skills, capability and resources to effectively engage consumers, including as appropriate, the inclusion of lived experience team members
- ☐ Ensure their research plan includes appropriate timelines to plan and support consumer involvement activities
- ☐ Ensure their research budget includes costs associated with supporting consumers (e.g., consumer engagement managers, translators, interpreters), supporting consumer involvement (e.g., travel costs/regional trial sites for rural and remote populations), consulting with consumers (e.g., events) and appropriately remunerating consumers for their time and contribution
- ☐ Ensure their risk management plan addresses consumer involvement in their planned project, including provision of effective support

To achieve best practice consumer involvement, MRFF-funded projects/grantees and their supporting research organisations would:

- ☐ Build and maintain ongoing relationships and partnerships with consumers and consumer organisations
- ☐ Ensure consumers are involved in the project at least as effectively as outlined in the grant application
- ☐ Ensure researchers and consumers are clear on their roles and responsibilities
- ☐ Provide effective support, training and information to consumers, including using plain language, culturally appropriate concepts and with awareness of any sensitives particular to that consumer group, to allow consumers to contribute to their full potential
- ☐ Provide an environment where consumer involvement is safe, sensitive and respectful
- ☐ Ensure sufficient consumer numbers to facilitate multiple voices and peer support amongst consumers
- ☐ Maximise return on investment by ensuring outcomes of research are shared (including through publication, but also through feedback to the community, health services and policy makers), and (where appropriate) translated into practice
- ☐ Ensure all consumers involved in the project receive regular feedback and updates on the results and outcomes of the project, including the value they have added
- ☐ Appropriately compensate and recognise consumers and community members for their involvement
- ☐ Ensure consumers are appropriately acknowledged in reports, presentations, etc ☐ Reflect and evaluate with consumers to inform continuous improvement
- ☐ Use progress and final reports to report on consumer involvement in their roject

Resource 6: What does 'consumer-led' mean?

Adapted from: 'Medical Research Future Fund – Preventive and Public Health Research Initiative 2023 Consumer-Led Research Grant Opportunity Guidelines'

5.4 "assessment criteria (consumer-led grant): "the appropriateness of the mechanisms for involving consumers in the research project, as outlined in the Consumer Involvement Statement"

5.5: "Applicants to this grant opportunity are required to involve consumers at all stages and levels of their proposed research, including in defining the research question and through the life of the proposed research and its translation"

F. **Consumer Involvement Statement (maximum two A4 pages)**
This section should be used to address all four Assessment Criteria. Your Consumer Involvement Statement should explain how you propose to involve consumers at all stages of the proposed research, including its design, conduct and translation. In your statement, please address all of the following:

describe how the needs, priorities, views and values of consumers (including people with relevant lived experience and their carers) have informed the research question
- describe how, when and in what roles consumers will be involved in the conceptualisation, development, planned translation and implementation of the proposed research

- describe how consumer involvement in the project is inclusive and diverse, as appropriate to the project (e.g. by age, gender, geographic association, socio-economic status, cultural and linguistic diversity), and (where relevant) explain why any particular groups are excluded

- provide details of how, when and in what roles consumers will be embedded in the ongoing conduct and dissemination of the research (e.g. project governance, project oversight, recruitment, consent, ethics, communications, publications)
- describe how you will provide a safe, sensitive and respectful environment for consumers involved in the project - provide details of how you will provide sufficient peer support for consumers (e.g. by providing more than one consumer on each committee)

- describe how you will provide effective support, training and information for consumers to ensure they contribute to their full potential

- explain how the project budget is adequate to support consumer involvement, participation and consultation (e.g. consumer engagement managers, translators, interpreters, travel costs, remuneration costs)

- explain how project timelines are adequate to plan and support consumer involvement activities

- describe how the research team has the skills, experience and capacity to involve and support consumers (including those with lived experience) in the proposed research appropriately and effectively.

Resource 7: What MRFF says about assessing involvement in grants

What are assessors looking for?

Consumer involvement in research projects
Examples of descriptors to strengthen consumer involvement in research and engagement with priority populations:
1) Project Impact: demonstrate how the views and values of consumers, the community, health providers and/or other end users have informed the proposed research
2) Project Methodology: describe how consumers have been involved in the trial design
3) Capacity, Capability and Resources to deliver the project: projects that specifically focus on the health of priority populations* should demonstrate that the research team includes leadership by the priority population
* 'Priority populations' include but are not limited to:

- Aboriginal and/or Torres Strait Islander people
- Older people experiencing diseases of ageing
- People with rare or currently untreatable diseases/conditions
- People in remote/rural communities
- People with a disability
- Individuals from culturally and linguistically diverse communities
- LGBTIQ+ people
- Youth

Adapted from: 'MRFF Webinar - Assessing MRFF Grants: Insights from Assessors 15 March 2023':
https://www.health.gov.au/sites/default/files/2023-03/medical-research-future-fund-webinar-assessing-mrff-grants-insights-from-assessors-15-march-2023-presentation.pdf Documents adapted under Creative Commons Attribution 3.0 licence

Resource 8: Example MRFF Scoring matrix

Assessment Criterion 1: Project Impact

The proposed research:
- comprehensively and convincingly addresses the objectives of the grant opportunity and will deliver against the desired outcomes
- is informed by an exemplary analysis of existing and ongoing studies in the field
- comprehensively and convincingly considers of the needs, priorities, views and values of consumers (particularly those with lived experience and their carers), the community, health providers and/or other end users
- demonstrates broad and meaningful involvement of relevant partners
- if successful, will rapidly and significantly improve health outcomes
- outcomes in the Measures of Success statement are highly relevant and meaningful to the goal and aims of the Initiative/Mission

Assessment Criterion 2: Project methodology

The proposed research:
- has a near-flawless design that is appropriate to the research question.
- The research is highly feasible with the required expertise, research tools, and techniques established.
- The proposal includes highly effective milestones and performance indicators.
- The research clearly and comprehensively articulates extensive involvement and contributions of consumers throughout the research journey.
- Where relevant, the proposal demonstrates comprehensive leadership and involvement of priority population(s) that the research is intended to benefit.
- Arrangements for governance and oversight of the project are well articulated and will ensure its successful delivery.

Assessment Criterion 3: Capacity, capability and resources to deliver the project

Relative to opportunity, the research team:
- has diverse expertise and experience that is highly relevant to all aspects of the proposed research.
- has, during the assessable period (considering career disruption), demonstrated outstanding impact through the translation or implementation of research findings.
- has comprehensively and convincingly demonstrated it has the skills, experience, and capacity to involve and support consumers appropriately and effectively.
- has clearly demonstrated the strong commitment and contribution of partners to the project and how they will support its successful delivery.

Adapted from: 'MRFF - Preventive and Public Health Research Initiative - 2023 Consumer-Led Research Grant Opportunity' at
https://www.grants.gov.au/Go/DownloadDocument?objectUuid=3a99e5dd-9146-4dc4-9f80-233014b6a480&documentType=GO&fileName=MRFF%20-%20Assessment%20Criteria%20Scoring%20Matrix.pdf
(note – log in required to access link. Not publicly accessible). Document adapted under
Creative Commons Attribution 3.0 licence

Resource 9: What are you doing to involve people?

How are the public involved in your work? Who is doing which tasks? This is an action-based approach to the spectrum of involvement, designed to aid discussion about **assessing current involvement and planning for future activities.** The pyramid gives an indication of how many people might be involved in each action.

Actions	Involve people by…
Innovating This includes prototyping, piloting, establishing, and creating new ways of doing things. This can include anything from building partnerships or buildings.	**Supporting them to:** • Design and carry out research • Create solutions • Implement ideas • Learn from actions
Managing, delivering and evaluating Working in partnership to manage ongoing activities.	**Having:** • Clear roles and tasks for the public • Elections and interviews when appropriate • Clear and accessible accountabilities for all roles (including staff), groups and committees. **Asking them to take actions such as:** • Managing or overseeing actions, processes and procurement • Directly delivering services or reviewing providers • Evaluating actions, processes and outcomes
Prioritising and planning Working in partnership to prioritise actions and plan implementation.	• Agreeing priorities in a clear, transparent way (this can include stopping certain actions) • Having clear accountabilities for planning at all stages • Having a transparent and adaptable budget
Listening, responding and acting Actively seeking feedback, responding to ideas, compliments and complaints with actions.	**Asking them to help:** • Interpret feedback • Influence responses to ideas, compliments and complaints • Asking for ideas for actions This includes telling people what this action was, particularly those who have given feedback.
Asking and discussing Asking people what they think, need and want and discussing it with them.	Inviting people from your intended audience or people you are trying to help to: • Design **how** you will collect feedback and **interpret** the results • Identify any potential barriers that might stop people from giving feedback.
Telling Giving information about what you have done, are doing or are going to do.	• Sharing opportunities to be involved • Asking people for ideas and support to share and disseminate what you want to tell people • Ask for feedback about how you are sharing information and attempt to measure the impact.

There are many things to think about when involving the public in research – starting with asking what words people prefer to use to describe themselves. This document is intended to help ask the right questions for the right roles.

How to use this resource: Under 'Assumptions and barriers', read the questions and consider if these might be barriers to involving some people, and consider how you might overcome these. 'Learning needs and support' examines the role in more detail and asks questions about the support people might need support to develop.

Be clear what you want– which stakeholders do you want to involve? Is it someone with specific experiences or skills? Is it someone with a lay perspective or just anyone who can give their time? Consider who you might unintentionally exclude by using these terms and be clear what **you** mean by *engagement* or *involvement*.

Assumptions and barriers	Role Description	Learning needs & support
• What commitment do you expect (time/financial implications) • Have you asked people to think about their emotional readiness? • Do you expect them to be reading and writing information and documents? Have you considered what formats might be appropriate? • Are you assuming a good ability to speak and read English? • Do you expect a certain educational background?	**Public/Community/Lay Leader:** A person who speaks and acts on behalf of all members of the public or specific communities, and takes a leading role in representing other lay representatives. The role may involve holding people or organisations to account. **Public/Lay representative:** a member of the public (not a professional) who is a representative. They must speak and act on behalf of others (including people with specific experiences). They may be guided by lay leaders but will be expected to take direct action to ensure that they are informed and able to represent the views of others.	**How are they supported to be a representative?** • How will they be gathering views? • Will this involve research? • Do they have a budget? • Should they be paid? • Is there admin and practical support (from an organisation?) • Is there any training available? **Who is already doing this?** • Are there any opportunities for them to be involved in peer support or have or be a buddy? • What can be shared with other organisations? (E.g. learning, resources) **How are people involved?** • Can people be involved in other ways? (e.g. is it face to face meetings? What can be done online, what cannot?)
• Are the people who have engaged with you the only people who might be interested?	**Interested and engaged members of the public:** People who know about and/or are interested in decisions being made, but may take no direct action other than giving feedback, being involved in a public dialogue or signing petitions.	**Could there be a need for translation?** • Are there any groups or organisations who could support with this? **Remember**: 'public dialogue' is not fully 'representative' but can give a strong indication of how the public at large feels
• It is easy to assume that people who are not engaged don't want to be. • Often they won't even know how they can contribute or be involved • Some may not be able to afford the time, caring responsibilities or travel.	**Uninformed, disengaged or disinterested members of the public:** people who, for what ever reason, are not engaged, informed or interested in influencing decision making or shaping the future of health and social services.	**A majority of the population are in this category**. • What information or support might some people need to help engage them or move them into other roles? • What might make people move back into this role? (e.g. not seeing direct improvements, or too much of organisational change?)

Remember: roles are not always fixed, they are often just a way of articulating different things people can or should do. Tasks can be more focused. There is always a way for dedicated people to give their time and develop their skills, what ever the label or role description

Resource 11: Ethics and involvement

Who decides who decides what is ethical?'

- Concepts such as 'involvement', 'ethics', 'democracy', 'integrity' and 'inclusion' cannot be easily defined, as they carry resonances of concepts such as **equality**, **justice** and certain '**rights**'
- At the root of the word 'ethics' is not one single definition, but an entirely subjective concept, expressed in English by the words 'fairness' or 'justice'
- Translating such descriptions between cultures and languages presents difficulties

In Australia, the 'National Statement on Ethical Conduct in Human Research' guides research conducted in Australia.[4]

Ethical involvement – why?

The Health Research Authority UK in partnership with the National Institute of Health Research published a briefing on the evidence for how public involvement can have an impact on research, and how public involvement in research can support the ethical review process by helping to:

- **make research more relevant** – so that the research results are more likely to benefit patients and the public
- define what is likely to **be acceptable** to participants – particularly in controversial or sensitive research
- **improve the informed consent process** – making it easier for prospective participants to understand the research and its potential risks and benefits
- **improve the experience of participating in research** – checking that the practical arrangements for participants are appropriate and a respectful use of people's time
- **improve the communication of findings to participants and the wider public** – providing information on the progress of the research as well as the final results.

Adapted from *https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/*

Grey area alert!

Differentiating between public involvement activities and qualitative research methods is complex – **seek guidance if you are unclear if additional ethics approval is required:**

"Engaging the public as research participants and treating their verbal contributions as data would always, in our minds, necessitate the gaining of ethical approval. This would, we believe, also apply if the information gained from consulting the public in the research design stage is presented as qualitative research data"

Extracts from "A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards"

Pandya-Wood, R., Barron, D.S. & Elliott, J. https://doi.org/10.1186/s40900-017-0058-y

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[4] https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2023

Aboriginal Health and Medical Research Council (AH&MRC) ethical guidelines

Summary of Five Key Principles

The Aboriginal Health and Medical Research Council (**AH&MRC**) ethical guidelines. See also Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics

- Ensure net Benefits for Aboriginal people and communities (including co-designing the research)
- **Aboriginal Community Control of Research** (ensure involvement, Aboriginal oversight and meaningful engagement at all stages of the project, support and that consent has been sought
- Cultural Sensitivity
- Reimbursement of costs
- Enhancing Aboriginal skills and knowledge

Adapted from https://www.ahmrc.org.au/wp-content/uploads/2020/06/V2.0-Key-principles-Updated.pdf

International best-practice

Ethical involvement - when and how?

- "Researchers who conduct studies in health and social care are encouraged to involve the public as early as possible in the process of designing their studies"
- "The process of ethical review does not consider how researchers work with patients and the public early on to design their studies"
- "there is no requirement for researchers to seek ethical approval for public involvement"
- "the ways in which researchers involve the public in the design of their studies are sometimes unintentionally unethical"

Extracts from "A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards" Pandya-Wood, R., Barron, D.S. & Elliott, J. https://doi.org/10.1186/s40900-017-0058-y

What is ethical research and what is ethical involvement?

The question of what is ethical research conduct, and what does ethical involvement in research look like is complex and ongoing – the diagram below seeks to articulate a flow chart to help work through the stage of the research, and if formal ethics approval from a Human Research Ethics Committee is needed for the planned method of involving people.

Do I need ethics to involve people?

The shortest answer to this questions – if you're not sure, seek guidance from ethics advisors. In Australia, all human research must be conducted in accordance with the 'National Statement on Ethical Conduct in Human Research 2023' (check for most up to date version).

What does 'best-practice' ethical involvement look like?

Whatever methods of involvement are being used, and whether or not formal ethics approval is required, the following are important considerations to ensure the involvement method aligns with best-practice:

- How have you involved different stakeholders in helping design your involvement plan?
- When recruiting people to be involved, is your method appropriate and inclusive?
- Is what is being asked of people involved reasonable (time-commitment, work-load, emotional considerations)
- Is your method of involvement inclusive? Are people supported to be involved? Are people paid for their time? If not, why? Are people paid for travel? Will people be provided with IT equipment and internet access? Will they be offered training and emotional support?
- Do you have formal documentation clarifying people's tasks, commitments and expected conduct (including any relevant legal documentation such as confidentiality agreements)?
- Have you asked for people's preferences about ways of working? Have you asked if people would like involvement to be anonymous or attributed? Will they be invited to be co-authors or presenters of the research?

Resource 12: Questions to ask about research

Questioning everything is at the root of the scientific method, that's what gives us knowledge. Good research attempts to answer questions using a rigorous method to give answers (or more questions!).

Critical appraisal is a way of looking at published or reported research and asking questions about the validity of the methods, the results and how published findings can be acted on.

Below are some basic questions to ask of any research before it moves on from the design stage. When answering these questions, try to start with what is good, and then move onto what could be improved.

Ethics – Are the participants being recruited in an acceptable way? Is it possible to have informed consent? Are participants paid and is this relevant? Are participants exposed to unnecessary risk? Are the exclusion criteria appropriate or too excessive? (e.g. gender, age or being pregnant are common exclusion criteria)

Need – Does the research question address something of importance to the public and patients? Does it look at clinical need or an uncertainty about current treatment or services?

Public involvement – Do you think the public and consumers have been involved in identifying the need for the research, the design of this research or any other stages? Is there any budget for public and consumer involvement? Is there any evidence of public involvement?

Research method – is the research question clear? Is the method valid? Do you need more information to answer these questions? Is the research new or has it been done before (e.g. has a systematic review been done)?

Translation – is it clear how this research could be useful? If not, how could it be better explained?

Research Funding – Who is paying for this research, is there a conflict of interest? Is the cost of this research justifiable when compared with other priorities? Who owns the findings, data and the ults (e.g. intellectual property)?

Dissemination - Will the results and data be published? Will this be publicly accessible? (this may help avoid research being repeated). Will any of the successes of involving the public be shared?

The questions below can be more helpful to ask for clinical research:

Patient experience – what issues might there be? Will this potentially improve the experience of future patients?

Information – How is information presented to potential participants? What is good, what could be improved? Does this affect ability to give informed consent? Are the risks and benefits clear? Is the timescale and commitment clear?

For more detailed information on critical appraisal, find some free resources from the Critical Appraisal Skills Programme at:

http://www.casp-uk.net

When working with others in a group or on a project, it can be helpful to make sure the following are as clear as possible:

Remit
- What is the purpose of the meeting/group?
- Are there any terms of reference? Does everyone have a copy?
- When they were last revised? Are they updated regularly?

Role
- Is each member clear about why they are there?
- What are people's expectations of you?
- Do you or others ever find that you have conflicting roles?
- What do others expect of you?

Representative
- Are you seen as a representative?
- If so, who are you supposed to represent? Do you have a constituency, a group of people whose views you aim to represent?
- How are you supported to be a representative? How might you gather people's views? How do you report back to them?
- Are you there because of a personal experience?

Responsibility
- What responsibilities do you or others have? (see terms of reference)
- Who sets the agenda? Is this responsibility shared?
- How are decisions made? How are they implemented? Who takes responsibility for reporting back and ensuring the wishes of the group are carried out?

Relationships
- Does it feel like being part of a team, everyone working together?
- Is there a sense of common purpose and goals?
- Do you get along with each other? Do you know each other as individuals or are you strangers brought together by your roles?
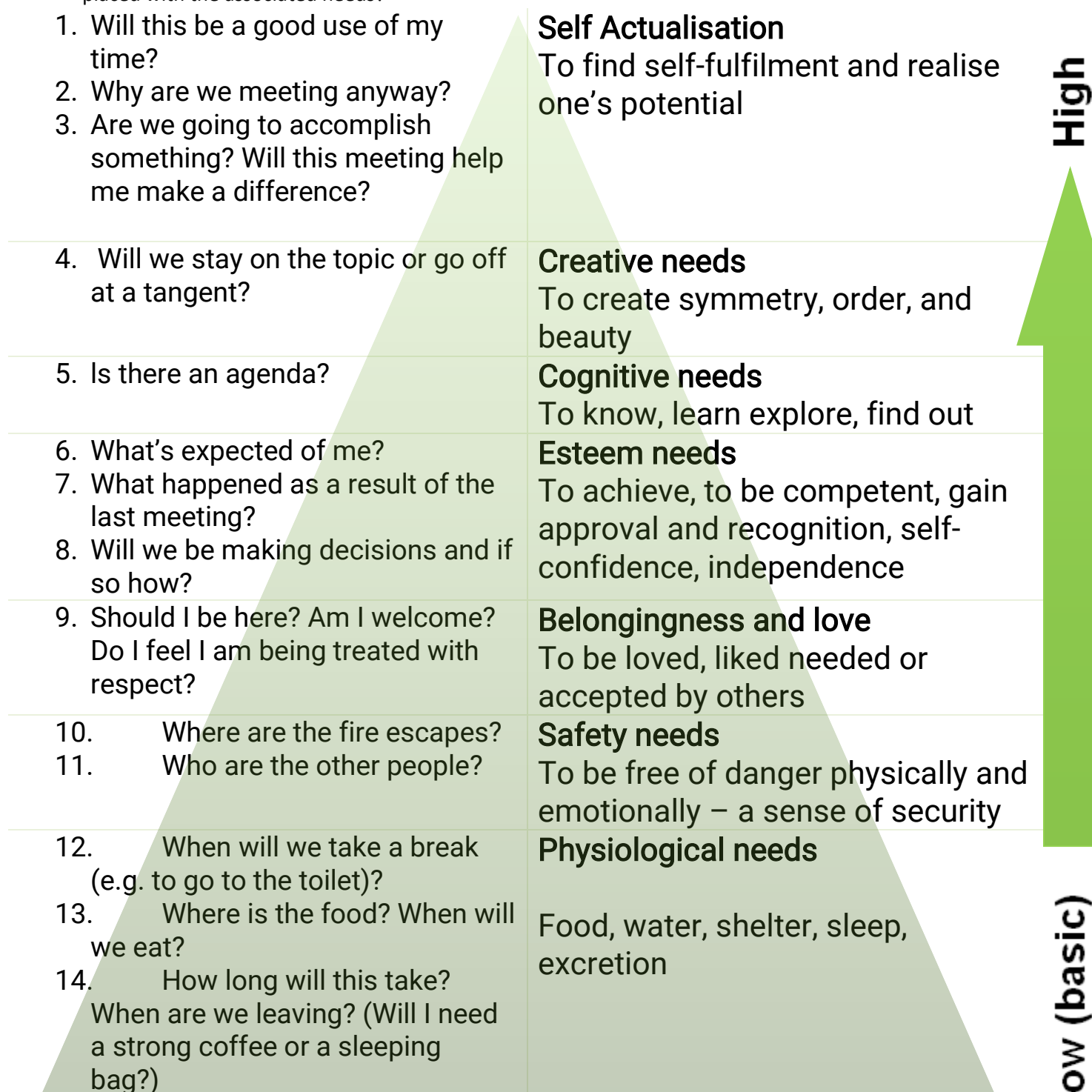
Readiness
- Are you ready to get involved? Have you considered your emotional readiness and any time commitments?
- Have you received any training to help you prepare for your role? Have you thought about how can you maintain and support your wellbeing?
- Do you know who or where you can go to for support regarding any of these issues?

Maslow's hierarchy of needs claims that needs that are **low** in the hierarchy must be partially satisfied before needs that are **high** in the hierarchy can be prioritised. Think of a hierarchy as a pyramid, 'low' meaning a basic foundation.

The answers to the questions on the left lie at the very heart of good meetings. They've been placed in an order to approximate to the hierarchy. Discuss whether you agree with the questions being placed with the associated needs?

Questions	Needs
1. Will this be a good use of my time? 2. Why are we meeting anyway? 3. Are we going to accomplish something? Will this meeting help me make a difference?	**Self Actualisation** To find self-fulfilment and realise one's potential
4. Will we stay on the topic or go off at a tangent?	**Creative needs** To create symmetry, order, and beauty
5. Is there an agenda?	**Cognitive needs** To know, learn explore, find out
6. What's expected of me? 7. What happened as a result of the last meeting? 8. Will we be making decisions and if so how?	**Esteem needs** To achieve, to be competent, gain approval and recognition, self-confidence, independence
9. Should I be here? Am I welcome? Do I feel I am being treated with respect?	**Belongingness and love** To be loved, liked needed or accepted by others
10. Where are the fire escapes? 11. Who are the other people?	**Safety needs** To be free of danger physically and emotionally – a sense of security
12. When will we take a break (e.g. to go to the toilet)? 13. Where is the food? When will we eat? 14. How long will this take? When are we leaving? (Will I need a strong coffee or a sleeping bag?)	**Physiological needs** Food, water, shelter, sleep, excretion

High → **low (basic)**

Questions adapted from Roberta's Rules of Order by Alice Collier Cochran Published by 2004.

Resource 15: Example plan for public involvement in an institution

On the next pages is an example of a strategy (or plan) to improve public involvement at an institution. It is shared here as a learning resource, and is not a version of a document in use or approved by La Trobe University.

Questions to consider:

- Is there anything in here you think would be helpful for your institution to plan to do?
- Is there anything missing or which could be improved?
- Who would you assign the different tasks to?
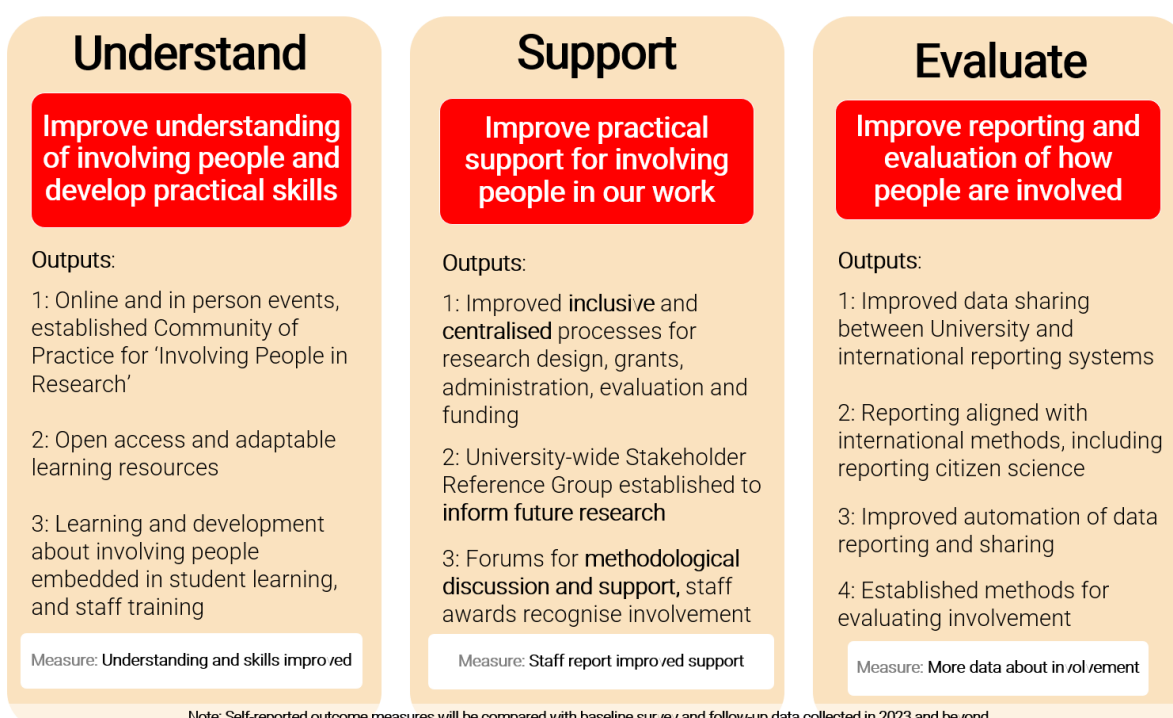- How would you report and evaluate the implementation of such a plan?

Example plan

To achieve the three broad goals in this plan, we propose a number of interconnected tasks. The tasks described below are organised by the three goals. For clarity, each task has been assigned an individual ID in relation to the goal (Goal 1 = **U**nderstanding, Goal 2 = **S**upport, Goal 3 = **E**valuate).

Goals

Improve:
1. skills and knowledge of researchers, staff, and students about public involvement
2. practical support provided by La Trobe University for involving the public in research.
3. data about public involvement activities

Summary of the Goals

Understand

Improve understanding of involving people and develop practical skills

Outputs:

1: Online and in person events, established Community of Practice for 'Involving People in Research'

2: Open access and adaptable learning resources

3: Learning and development about involving people embedded in student learning, and staff training

Measure: Understanding and skills improved

Support

Improve practical support for involving people in our work

Outputs:

1: Improved **inclusive** and **centralised** processes for research design, grants, administration, evaluation and funding

2: University-wide Stakeholder Reference Group established to **inform future research**

3: Forums for **methodological discussion and support,** staff awards recognise involvement

Measure: Staff report improved support

Evaluate

Improve reporting and evaluation of how people are involved

Outputs:

1: Improved data sharing between University and international reporting systems

2: Reporting aligned with international methods, including reporting citizen science

3: Improved automation of data reporting and sharing

4: Established methods for evaluating involvement

Measure: More data about involvement

Note: Self-reported outcome measures will be compared with baseline survey and follow-up data collected in 2023 and beyond

Goal 1: Improved understanding

This goal is focused on enhancing La Trobe researchers' understanding of the importance and benefits of public involvement in research.

What and when	How	Evidence of success
U1.1 Enhance researcher awareness of the contribution of public involvement to the quality, relevance and impact of research	A series of tailored learning events in Schools, Departments and Research Centres	Number of learning events, number of participants, positive feedback for event, consultation with 20 researchers (HDR though level E) about awareness of public involvement
U1.2: Maintain 'Involving the public in research' Community of Practice, with six forums annually (ongoing)	Promotion through research mailer, DVCRIE newsletter, ADRIE. Community of Practice meetings chaired by Public Involvement Strategic Lead	Six annual meetings, number of participants at meetings, positive feedback from participants that have attended
U1.3: Produce guidance for researchers on ethical issues related to public involvement in research	Review best practice guidelines nationally, discussions with La Trobe researchers and chair of the HREC (Human Research Ethics Committee)	Guidance on ethical issues related to public involvement is available on the La Trobe ethical committee web pages and open access. Positive feedback on guidance from La Trobe Researchers.
U1.4: Enhance how public involvement is described and evidenced in La Trobe led grant applications (ongoing)	Organise workshops (around March and September 2024) on improving public involvement in projects seeking grant funding, with a focus on improving descriptions of public involvement activity	Number of learning events, number of participants, positive feedback about events

What and when	How	Evidence of success
U2: Create and curate a repository of open access and adaptable learning resources about involving the public in research	Create learning materials about involving the public in research which are open access and can be adapted into multiple formats, reused, translated and shared; and link to existing resources	Number of learning resources created, usage and positive feedback on open access learning resources
U2.2: Create and deliver an "Introduction to public involvement" learning resource specifically for higher degree research students U2.3 Embed public involvement as a core element of training for higher degree research supervisors	Create learning materials about involving the public in research which are open access and can be adapted into multiple formats, reused, translated and shared and integrated into existing courses, training and resources	Number of learning resources created, positive feedback on learning resources
U3.1: Establish and maintain a university network of 'Public Involvement in Research Champions'	Recruit, train and support a network of 'Public Involvement Champions' who can support public involvement in research	Number of staff and researchers recruited, trained and supported to be 'Public Involvement in Research Champions' in Schools

Goal 2: Improving practical support for involving the public in research

Goal 2 is focused on improving the practical support La Trobe University provides to researchers for involving the public in research.

Task	How	Evidence of success
S1.1: Standardised processes for reporting public involvement in research (integration with PRIME)	Provide appropriate resourcing to develop and maintain clear processes for reporting public involvement in research, including impacts and outcomes	Number of grant applications where public involvement has been supported, number of projects with involvement reported in PRIME, number of projects which have and evaluated impacts and outcomes of involvement
S1.2: Ensuring inclusive research practices by providing financial support for public involvement activities, including maintaining internal university processes (end of 2024)	Provide more funding to directly support public involvement in research, including funding for the time of the public involved in La Trobe research, and relevant partner organisations where appropriate	Number of grant applications supported, number of projects with involvement funded, reported and evaluated. University policies aligned with relevant national guidelines.
S1.3: Develop policy for paying the public for their involvement in research (end of 2025)	Develop guidance for researchers for paying people for their involvement, and co-design a university Policy	University policy on involving the public and payment, and resourcing to administer and evaluate processes
S1.4: Consistent support and administration of public involvement	Provide appropriate resourcing to consistently administer payments and reporting of involvement activities across the University.	
S1.5: Database of public involvement exemplars	Develop a publicly accessible database of examples of public involvement in projects	Publicly accessible information about successful grant applications, research protocols, publications and reports of public involvement and any impacts.
S3.1: Explore a staff award recognising excellence in public involvement in research (end of 2025)	Provide appropriate resourcing to assess and reward staff and researchers for involving the public in research	Staff award recognising involvement

Task	How	Evidence of success
S4.1 Support for open access publishing	Continue to promote and support open access peer-reviewed publishing, and scope resourcing required to ensure that knowledge and learning generated by La Trobe will is publicly accessible	Increased number of open access publications and knowledge items, and improved accessibility of knowledge
S6: Public Involvement in Research Strategy Committee	Work with the Research Strategy Committee to explore how to integrate public involvement into the decision-making processes of the Research Strategy Committee	Positive feedback from staff and members of public involved in processes
S7: Public Involvement in School Research Committees	Work with the School Research Committees to explore how to integrate public involvement into their decision-making processes	

The following actions are proposed for a later stage of the plan

Task	How	Evidence of success
S2.2: University-wide Stakeholder Database established and developed to inform future research	Provide appropriate resourcing to establish and maintain a University-wide Stakeholder Database of people involved with research being conducted at La Trobe, working with existing CRM	Stakeholder Database established positive feedback from participants, researchers and other stakeholders
S3.2 Interdisciplinary academic forums for methodological discussion and support for public involvement	Provide appropriate resourcing to host interdisciplinary academic discussion about public involvement in research, and appropriate methodologies	Learning and development opportunities integrated into staff training and student learning
S3.3 Support novel approaches for public involvement in research	Scope pathways to providing resourcing to develop, run and evaluate novel methods for transparent collective decision making to inform research, such as priority setting partnerships, citizens' juries and online tools for integrating multiple stakeholders' preferences	Novel methods for transparent collective decision making are developed, run and evaluated
S4.2 Build capacity to integrate research findings into open knowledge infrastructures, such as Wikipedia (by end of 2025)	Initiate partnerships with trusted open knowledge infrastructures (such as Wikimedia Australia) and provide resourcing to support staff and students to integrate results and learning from our research (for example, supporting a 'Wikimedian' in residence	Improved research and knowledge dissemination in open knowledge infrastructures, improved accessibility, reach and impact of La Trobe's research

Goal 3: Improved data about public involvement activities

Goal 3 is to improve the data we have about public involvement in research, by improving data collection, and improving how we report and evaluate public involvement.

Task	How	Evidence of success
E1.1: Standardise internal terminology university-wide for reporting and evaluation of public involvement and associated impacts	Support the creation of a resource to support staff, researchers and students to report and evaluate public involvement using standardised terminology, using automated processes where possible	Standardised terminology used for internal reporting and integrated into internal reporting systems
E1.2: Improve data sharing about public involvement between University and international reporting systems (by 2024)	Provide resourcing to promote publicly accessible data sharing about public involvement and citizen science, aligning with both internal reporting (PRIME) and international reporting systems	Improved data sharing between University and publicly accessible international reporting systems
E1.3: Develop partnerships with relevant national and international organisations which report and evaluate public involvement in research, and publicly commit to supporting evaluation and reporting of public involvement (by 2024)	Publicly commit to supporting evaluation and reporting of public involvement (for example, signing the 'Shared Commitment to Public Involvement in Health and Social Care Research'	Number of research projects which have shared publicly accessible data about public involvement in research, statements of commitment to support public involvement in research
E.2.1: University-wide assessment of public involvement to identify current public involvement in research, best practice and the support needs of staff, researchers and students and the public (by March 2024)	Provide appropriate resourcing for surveys and additional interviews	Number of respondents to surveys, and participants in other qualitative research
E4: Improve HREC assessment and data collection about public involvement in relation to proposed research	Embed a question about public involvement in the HREC application	Positive feedback from staff, HREC members and researchers

Resource 16: Slides for the webinar 'Introduction to Public Involvement'

These slides were used in the webinar 'Involving People in Research' on March 14th 2024. A recording can be found here: https://archive.org/details/involving-the-public-in-research-2024.03.14

Involving People In Research

Jack Nunn

Public Involvement Strategic Lead
Research Grant Development and Transformation, Research Office

March 2024

Aims

Explore the concept of involving people in research

Explore why, who and how people can be involved in research

Explore current support and support needs

Outcomes

Explain **the importance of evidence-informed methods of participatory research**

Explain ways of planning, reporting and evaluating research

Improve La Trobe's Public Involvement Strategy

What does involving people mean?

When people are actively and transparently involved in the development, implementation, and evaluation of **policies, initiatives, research** and **services** that impact them

Defining participatory research

'an approach to research where research is carried out "with" people rather than "on" them'

WikiData definition, 2020

Other related terms include community-based participatory research, co-design and forms of 'public involvement', 'patient involvement' and 'consumer involvement' or 'community engagement'.

Getting the language right

'Who is involving who?'

- Words like 'participation', 'involvement' and 'engagement' can mean different things and can imply very different power relationships

- While it is important to ask 'who is involving who', a more helpful question can be '**who is working with who, how and why**?', 'Who is doing which tasks?'

- Who is not involved, and why?

- Who is a 'stakeholder' – someone who has a stake in the research outcome – and who is not? (and 'who is being paid?'…)

- How do people want to be described? Have you asked?

- Who decides who decides what is ethical?
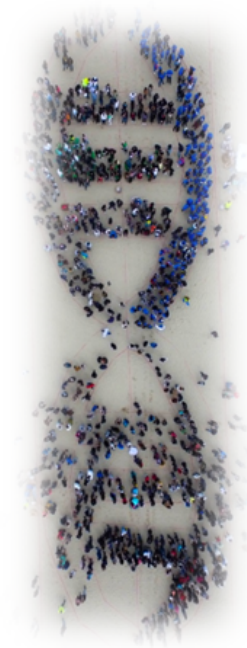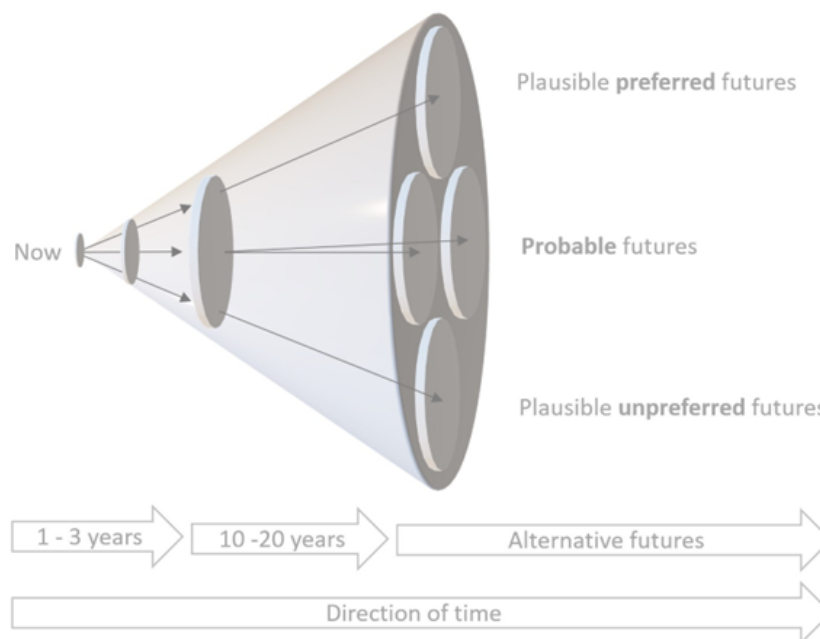
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Why involve people in research?

Plausible **preferred** futures

Probable futures

Plausible **unpreferred** futures

Now

1 - 3 years | 10 -20 years | Alternative futures

Direction of time

Adapted from Bezold C, Hancock T. 'An Overview Of the Health Futures Field' for the WHO Health Futures Consultation. 1993.
https://apps.who.int/iris/bitstream/handle/10665/61479/WHO_HST_93.4_eng.pdf

Why involve people in research?

MRFF
NHMRC
ARC
More to follow

$

Now

Plausible **preferred** futures

Probable futures

Plausible **unpreferred** futures

1 - 3 years → 10 -20 years → Alternative futures →

Direction of time →
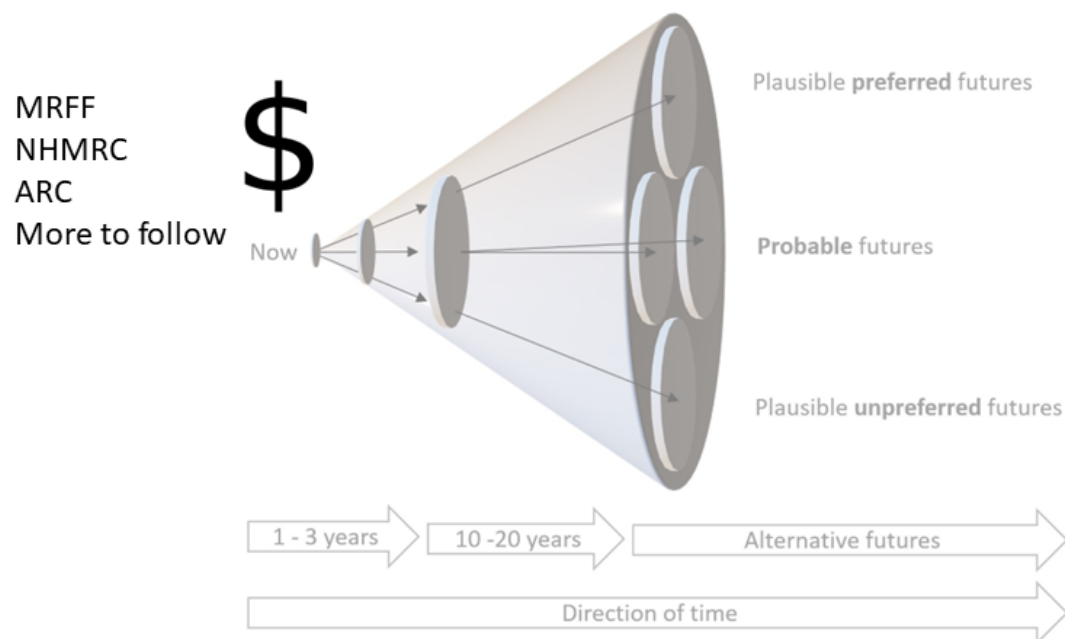
Adapted from Bezold C, Hancock T. 'An Overview Of the Health Futures Field' for the WHO Health Futures Consultation. 1993.
https://apps.who.int/iris/bitstream/handle/10665/61479/WHO_HST_93.4_eng.pdf

Why involve people?

- **make research more relevant** – so that the research results are more likely to benefit patients and the public

- define what is likely to **be acceptable** to people – particularly in controversial or sensitive research

- **improve the communication of findings to participants and the wider public** – providing information on the progress of the research as well as the final results.

Human research

- **improve the informed consent process** – making it easier for prospective participants to understand the research and its potential risks and benefits

- **improve the experience of participating in research** – checking that the practical arrangements for participants are appropriate and a respectful use of people's time

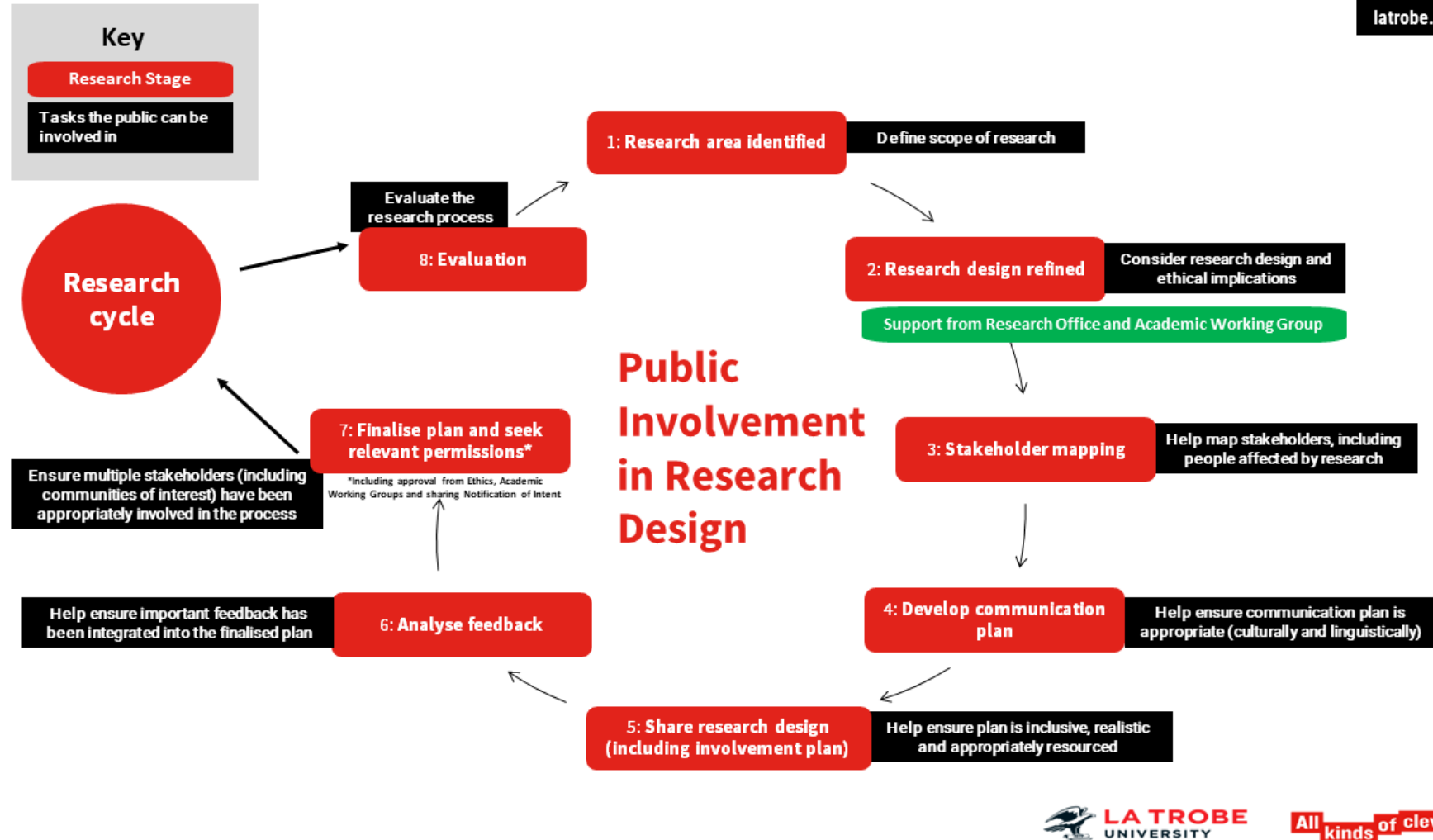Adapted from https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/

Purposes of involvement and measurable indicators

Purpose of involvement	Measurable indicators
Obliged: There are legal or other codified power constructs in place which oblige involvement in initiatives and research	• Public statements about methods or paradigms of involvement • Public policy • Support for people to get involved • Reported actions • Evidence of funding for involvement
Post-positivist: lived (subjective) experience and knowledge is valued equally alongside other kinds of knowledge and data	
Evidence-informed: There is evidence which suggests that involving people improves the quality and direction of initiatives and research	**Data sources can include:** Peer-reviewed papers, governance documents, legal or government documents, legislation or policy documents, publicly accessible websites
Self-evident: The concepts of ethics, human rights and democracy demand involvement	
Foundational principle	
Those affected by initiatives are the people most appropriate to help design, deliver and evaluate it	

Adapted from: 'Standardised data on initiatives—STARDIT: Beta version',
Nunn, J.S., Shafee, T., Chang, S. et al. 2022, doi.org/10.1186/s40900-022-00363-9

Identifying topics

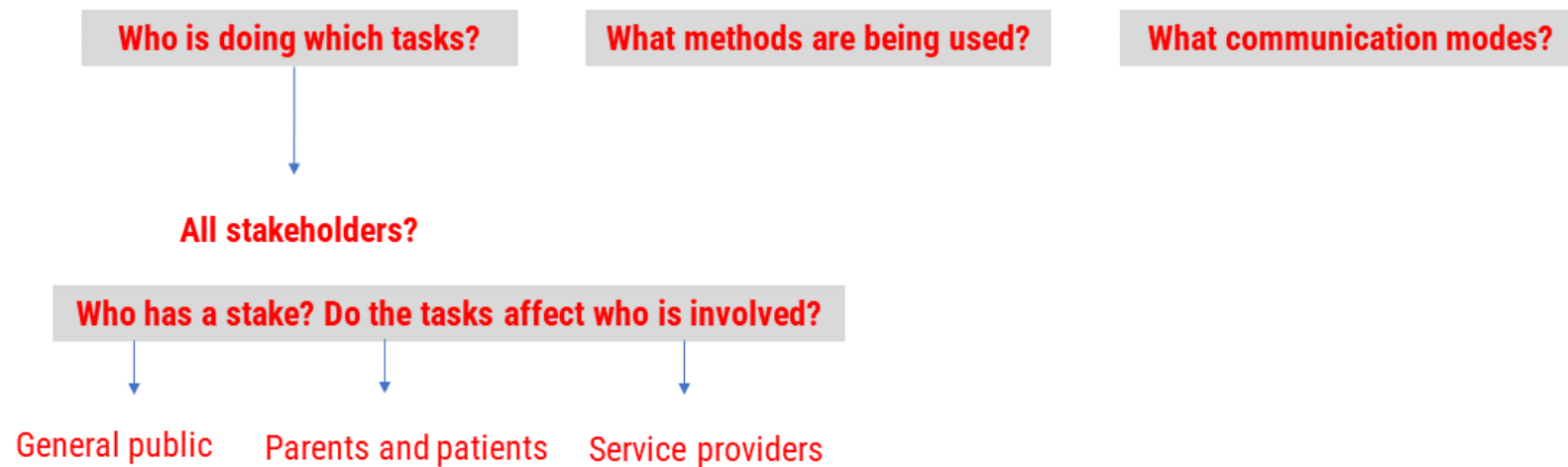Suggest research areas

Evaluation

Evaluate research outcomes and impacts, evaluate research process, evaluate methods of involvement, report impacts and outcomes of involvement

Prioritisation

Inform priorities

Research design

Designing and funding

Advise on methods and ethics, stakeholder involvement, appropriate funding sources

Public Involvement in Research

Implementation

(Research translation)

Advise on implementation plan, actively implement research findings through direct action

Research plan approved

Do research

Be part of research team, inform research via formal group

Share learning

(Dissemination)

Advise on dissemination plan, actively share learning

Data collection and analysis

Collect data, analyse data

Key

Research Stage

Tasks the public can be involved in

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Key

Research Stage

Tasks the public can be involved in

Research cycle

Public Involvement in Research Design

1: Research area identified — Define scope of research

8: Evaluation — Evaluate the research process

2: Research design refined — Consider research design and ethical implications

Support from Research Office and Academic Working Group

3: Stakeholder mapping — Help map stakeholders, including people affected by research

7: Finalise plan and seek relevant permissions* — *Including approval from Ethics, Academic Working Groups and sharing Notification of Intent

Ensure multiple stakeholders (including communities of interest) have been appropriately involved in the process

4: Develop communication plan — Help ensure communication plan is appropriate (culturally and linguistically)

6: Analyse feedback — Help ensure important feedback has been integrated into the finalised plan

5: Share research design (including involvement plan) — Help ensure plan is inclusive, realistic and appropriately resourced

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What is ethical research?

Public involvement in **deciding** and **overseeing** what is ethical

→

Ethical public involvement in the research

→

Best practice public involvement requiring **no additional approval**

↓

Best practice public involvement which **requires ethics approval**

If you are unclear, seek guidance

↓

Qualitative methods inform research

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Who can be involved and how?

Who is doing which tasks?   **What methods are being used?**   **What communication modes?**

Who can be involved and how?

Who is doing which tasks?   **What methods are being used?**   **What communication modes?**

All stakeholders?

Who has a stake? Do the tasks affect who is involved?

General public   Parents and patients   Service providers

Who can be involved and how?

Who is doing which tasks?   **What methods are being used?**   **What communication modes?**

Co-what?

Consultation? **Co**-creation? **Co**-investigator?

Survey   **Co**mmittee   **Co**lleague

Who can be involved and how?

Who is doing which tasks?   **What methods are being used?**   **What communication modes?**

In person or remote?

Which modes suit different stakeholder groupings best?

Letters   **Video calls**   **In person meetings**

Evidence informed participatory research

Reporting research processes in a standardised way using 'Standardised Data on Initiatives' (STARDIT) can mean that impacts from research processes can be reported, and involvement methods can be compared to other similar studies in the future.

Learn more: 'Standardised data on initiatives—STARDIT: Beta version',
Nunn, J.S., Shafee, T., Chang, S. et al. 2022, doi.org/10.1186/s40900-022-00363-9

Planning Template
(see Resource 3)

Section	Data fields	Guidance for completing the data field		
Initiative context	Initiative name	What is the name or title of the project, initiative or research?		
	Initiative type	Is it research, arts, education, policy, information, media, product, health and social care services?		
	Description	Summarise the project in 1500 characters in plain language as if writing for a 'non-expert' audience		
	Aims	What are the goals, objectives or purpose of this initiative?		
	State	Is this report about an initiative which is prospective, ongoing, or completed?		
	Location	What is the geographical scope of this initiative? For example, 'Australia' or 'global'		
Report Authors	Report authors	Who wrote this report? Who checked the report? Who contributed in other ways (such as editing information)		
	Contact	Is a report author a contact for the initiative? Is the report author affiliated or unaffiliated with the initiative?		
Contributor information	Contributors	**Type**: Who will contribute to this initiative? This can be an 'individual', 'grouping of individuals' or an 'organisation'. Example: 'Grouping of individuals'	**Name**: What is the name of the individual, grouping of individuals (number?) or organisation? Example: Project Steering Committee (10)	**Tasks** (current status): What are the tasks of individual, grouping of individuals or organisation (or planned or completed)? Example: project design (completed), management (ongoing) and data analysis (planned)
	Method	How will this contributor involved? Example: formal committee with Terms of Reference		
	Communication	What modes of communication will be used? Example: In person meetings, video calls, shared online documents?		
	Recruitment	How will people be recruited or invited to contribute to the initiative? Example: Public web-link, email invite		
	Compensation	How will this contributor be compensated or remunerated? Example: payment, honorarium, gift, no compensation		
	Cost	What was the estimated financial cost for involving each individual, grouping or organisation who contributed?		
Other inputs	Financial	What are the estimated financial inputs for this project (how much will it cost?), describe who is paying and provide and public links to information		
	Time and 'other'	How much time is being given to this project? For example, 'in-kind', pro bono or voluntary hours? Any other resources?		

Example of completed STARDIT Report

La Trobe University - Lived Experience Diabetes Reference Group

Description: STARDIT report about study protocol 'Establishment of a research ready Consumer Reference Group. (1) Background: Type 2 diabetes (T2D) has been understood as a progressive, nonreversible condition. However, recent research has shown that it is possible for people with T2D to achieve a glycosylated haemoglobin A1c (HbA1c) of under 6.5% and sustain this level for at least three months, without the need for medication, which reflects the concept of 'T2D remission'. Low carbohydrate diet (LCD) restricts the intake of carbohydrates to 5-10% of total calories and when compared to control diets, can lead to almost two-fold higher rates of T2D remission at 6 months. This is of importance since the current guidelines for General Practitioners (GPs) provide only general dietary recommendations for people with T2D. The above combined with the absence of initiatives that empower people with T2D actively engage in research that concerns them, led to the conceptualization of the proposed project. (2) Methods: This research project consists of four main phases. Phase-I will ensure appropriate governance of the project and establishment of an Interim Reference Group (IRG). Following an initial consultation with key stakeholders from Diabetes Australia, the Defeat Diabetes Program and Eastern Health Phase-II will invite community members with T2D to participate in a training workshop

Aims

1. To identify people with lived experience in Type 2 Diabetes (T2D) (referred as "consumers") and establish a research-ready "Consumer Reference Group" (CRG).
2. To empower consumers to actively engage in research that concerns them (i.e., train the CRG members on the research process and the co-design of consumer-led and other participatory research projects).
3. To understand consumer's unmet needs as a means to increase their self-efficacy in the management of their health condition (i.e., T2D).
4. To explore consumers' views and perceptions on barriers and facilitators of technology-enabled, low in carbohydrate diet interventions for tackling T2D.

Keywords
diabetes, co-design, personalised nutrition, participatory research

Category
research

Location
Australia

Dates
State prospective
Start 2023-11-01
Form updated 2024-01-22

Report authors
Katerina Sarapis
0000-0002-3397-8588
Main report author
Jack Nunn
0000-0003-0316-3254
Supported with report writing
Yingting Cao
Supported with report writing
George Moschonis
Supported with report writing

Inputs

group of individuals	organisation	group of individuals	time	time	time
Academic Investigators (6) **Task:** Project design, ethics applications, planning and delivering co-design processes, analysing data from co-design activities, manuscript preparation. **Method:** Formal investigator team, formal meetings and email discussions, commenting and editing documents. **Communication:** Teleconferences, face-to-face meetings, emails, shared online documents. **Compensation:** volunteer	Diabetes Australia, Defeat Diabetes and Eastern Health **Task:** Bridging between the consumers and academic investigators, contribute to all relevant activities, including consumer recruitment and key contact points for both consumers and the academic investigator team. **Method:** Project Advocate Committee, formal meetings, email discussions, shared online documents. **Communication:** Teleconferences, email discussions, shared online documents. **Compensation:** volunteer	Lived Experience Diabetes Reference Group representatives and members (10) **Task:** Involved in the co-design of a consumer-led research project (i.e., review/provide feedback on project concepts, protocols, ethics applications preparation etc). **Method:** Face-to-face and online events, training workshops, focus groups and other activities to involve people. **Recruitment:** Invitation by partner Organisations (Diabetes Australia, Defeat Diabetes and Eastern Health) **Communication:** Face-to-face, online meetings, emails, shared online documents. **Barriers:** Availability/capacity will make involvement difficult. **Compensation:** gift **Impact:** Co-design and evaluation of the research protocol and research plan.	A number of academic investigators volunteered their time co-creating this protocol. hours	Key stakeholders and consumer representatives from Diabetes Australia, the Defeat Diabetes Program and Eastern Health volunteered their time in recruiting study participants/consumers and in other activities related to the project. hours	Lived Experience Diabetes Reference Group representatives and community members volunteered their time to support the co-creation of this protocol. hours

Outputs and impacts

learning item	knowledge translation	publication/report/document
Identify and establish a Reference Group of people living with Type 2 Diabetes. **Impact:** Empower people with T2D to actively engage in research that concerns them	Enhance the interaction and collaboration between people living with Type 2 Diabetes, health professionals and researchers **Impact:** Increase self-efficacy in managing T2D and promote well-being in the communities.	Peer reviewed article describing the study design for the establishment of the Reference Group and the associated qualitative research **Impact:** Published protocol

Categories: STARDIT reports | Research STARDIT reports | STARDIT version beta reports

Adapted from: https://wikispore.wmflabs.org/wiki/La_Trobe_University_-_Lived_Experience_Diabetes_Reference_Group (March 14th 2024)

Questions to consider

- What support do we already have (people, non-human resources?)
- What would be helpful?

Group discussion

Resource 2

Group activity 1 'Stakeholder Mapping'

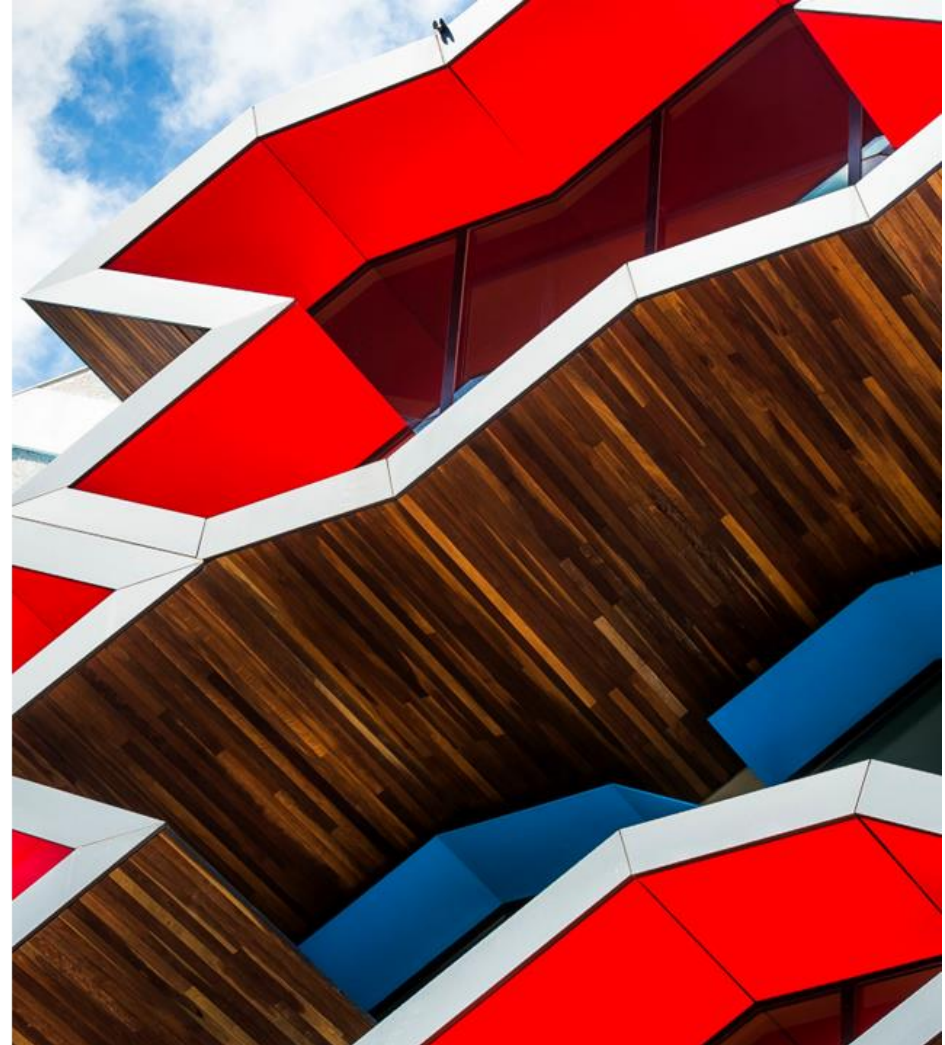Group Activity 2: Which stakeholders are doing which tasks?

Contact

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Thank you

latrobe.edu.au

Detailed contents

End of the document